

Governor Proposes to Eliminate TEFRA 134 Medical Assistance Coverage for Children with Disabilities (2/28/95)

Governor Arne Carlson has proposed to eliminate TEFRA Medical Assistance (M.A.) coverage for 3900 Minnesota children with significant disabilities who live with their families. TEFRA eligibility allows children to obtain Medical Assistance benefits even though their families are working and thus over the poverty line (\$15,150 for family of 4). These families are required to continue to buy private health coverage, if available, as well pay for the Medical Assistance services on a sliding fee basis. Medical Assistance pays for a variety of health care services needed by children with significant disabilities which are not covered by private insurance or HMO plans. Children on the TEFRA program used \$25 million (state 47%, federal 53%) in health care services through the Medical Assistance program (March 1994 DHS data). Home care services including private duty nursing and personal care assistant services accounted for 2/3 of the \$25 million. The remaining 1/3 was spent on therapies, durable medical equipment, medications, hospitalization, and other acute care health services which were not covered by private insurance. Private coverage is required by law to pay before Medical Assistance will cover the health care service.

The Governor's proposal will save the state an estimated \$11 million over the course of 1 1/2 years. The \$11 million state savings can be translated into nearly \$24 million when matched with federal money to provide health care services to children with significant disabilities in Minnesota. The Department of Human Services (DHS) proposes to redirect at least some of the 3900 children to other programs for persons with disabilities. The Department has provided no details on how much will be reinvested in other programs and how children and families will access these other services. We have been told that for children who qualify as having "mental retardation or a related condition," DHS will ask the federal government for approximately 500 more "waiver slots" to serve at least some of the TEFRA children. We are also told that the current budget provides for 200 more waiver slots for each of the next two years. Apparently then, the Department will use all new waiver slots available for the next two years for children whose condition meets the level of care needed in an intermediate care facility/mental retardation or related condition.

While some families with children using the TEFRA program and personal care assistant services available through the TEFRA Medical Assistance Option would certainly welcome the offer of a waiver slot, the number of new waiver slots will not serve all children with developmental disabilities who currently use the TEFRA Option to access medical care and/or personal care assistant services. It is also important to remember that there is currently a waiting list of 1100 individuals for the MR/RC waiver. There are many adults living with, aging parents who desperately need out-of-home residential services provided through this waiver. How will this need be met as well as the needs of 3900 TEFRA children with 900 additional waiver slots? DHS in the past has estimated that at least 2/3 (2,600) of the TEFRA children qualify for mental retardation/related conditions (DD) waiver.

In addition to MR/RC waiver slots, the Department of Human Services will request more waiver slots for the Community Alternatives for Disabled Individuals (CADI) waiver for children otherwise eligible for nursing facility level of care and the CAC waiver for children otherwise eligible for hospital level care. The Department has no details about how many children will be eligible for the CADI and CAC waivers and how many slots will be requested from the federal government. We are cautioned not to count on the federal government for more waiver slots at this time because of impending cuts in the Medicaid budget. The Department's proposal only promises to request new waiver slots from the federal government, there is no guarantees that the federal government will provide the slots. The Department is also not promising that all 3900 children now receiving health care coverage through the TEFRA Option will get a waiver slot or any other service. Thus far most people have acknowledged that some children will simply be dropped from services altogether.

For children with mental health diagnoses on the TEFRA program, there is no alternative waived services program available. We are told that some "funds" will be transferred into children's mental health services at the county level. For families who use the TEFRA program to pay for day treatment services, psychiatric and psychological therapy and medications, providing money to the counties will be useless. DHS staff have stated that children with mental health diagnoses, in particular, attention deficit hyperactive disorder (ADHD), really don't benefit from PCA service but may need other services instead. These other services are undefined and we are not being told how much money will be transferred to the counties. The consequences for children with mental health diagnoses are a bit more difficult to track than for children who would otherwise be in other Medical Assistance funded facilities. It is extremely urgent that families with children with mental health needs carefully describe the services their children are using paid for by TEFRA, and the consequences of not funding these services. In other words, what are the fiscal consequences of the elimination of the TEFRA program for children with mental health diagnoses, especially ADHD.

The TEFRA Medical Assistance Option requires parents to pay on a sliding fee scale. The most recent data that I have been able to obtain shows that parents are paying over \$600,000 annually in parent fees to buy into the Medical Assistance benefit set for their children with severe disabilities (includes both in and out of home care). These parents are required by law to continue buying private health coverage, if available, which is to be used first before Medical Assistance coverage. The Department of Human Services has stated that TEFRA families make over the poverty level incomes and therefore should be able to pay out-of-pocket for services needed by their children. In addition, DHS maintains that these families have private insurance and therefore don't really need Medical Assistance services.

If only 5% (195) of TEFRA children end up in regional treatment placement at \$324 per day, the state savings evaporates. Hospitalizations will cost even more. There are no nursing homes for children, but the state may well need to establish some if this proposal is passed.

Anyone currently using the TEFRA 134 Medical Assistance Option who is concerned about its elimination, should write to the Governor and their senator and representative. The proposal to eliminate TEFRA is put forth by the Governor but must be passed by the Legislature. Detailed information must be provided to officials about services not covered by private insurance (use figures), out-of-pocket uncovered expenses, consequences and alternative care options for your child with severe disabilities, and especially fiscal consequences. In addition to providing this information to the Governor and your senator and representative, please make a copy and send it to Anne L. Henry, Minnesota Disability Law Center, 430 First Avenue North, Suite 300, Minneapolis, MN 55401-1780. For the name and address of your state senator, call 612/296-0504. For the name and address of your state representative, call 612/296-2146. The Governor's phone number is 612/296-3391, Governor Arne Carlson's address is: 130 Capitol, Saint Paul, MN 55155.

There will be a hearing on the Governor's proposals for PCA cuts and restructures and TEFRA elimination on Wednesday, March 22, 1995 at 2:00 P.M. in Room 118 of the State Capitol.

Governor's PCA Cuts And "Restructuring," 2/28/95

In his supplemental budget request to the Legislature, Governor Ame Carlson proposed that the personal care assistant (PCA) program through Medical Assistance be significantly restructured and reduced in funding. The Governor's proposal is to retain the current PCA program only for those adults who can direct their own care. DHS estimates that there are currently 6,000 recipients of PCA services in Minnesota. Children under 18 years of age make up 54 percent of current PCA recipients, 38 percent are between 18 and 64 years of age, and 8 percent are over 65 years of age. The Department of Human Services (DHS) estimates that nearly half of the adults on the PCA program are able to direct their own care, thus from 3/4 to 4/5 of current PCA recipients (4500 to 4800) will no longer be eligible for the existing PCA program. Categories affected include all children, adults with mental retardation, mental illness, traumatic brain injury, Alzheimer's, and any other condition which impairs one's ability to direct the PCA, i.e. direct when and what medication must be taken and when and what services need to be performed.

DHS has stated that they will "reinvest" the PCA savings in other waiver programs for persons with disabilities in order to serve people more appropriately. The waiver programs affected include: 1) the developmental disabilities waiver (known as mental retardation related condition, MR/RC), 2) the CADI waiver for persons otherwise eligible for nursing home care, 3) the CAC waiver for persons otherwise eligible for hospital care, 4) the traumatic brain injury waiver for people with TBI who would otherwise be in a nursing home or hospital, and 5) the elderly waiver. The Department has been unable to provide any figures on the amount of money to be "reinvested" in these waiver programs and the number of current PCA recipients who would be transferred to benefit from waived services.

PCA services are available through the waiver programs, but only if one also buys case management. Currently all other services offered as part of the developmental disabilities (MR/RC waiver are more expensive than PCA services. Every waiver requires case management, which costs \$60 per hour (over five hours of PCA service) for the MR/RC waiver. It is clear that DHS will not be able to provide all of the 4500 to 4800 PCA recipients with a waiver slot. Even if all 4500 to 4800 PCA recipients were given a waiver slot, everyone would receive less service because waived services are more expensive than PCA services. This is a fair conclusion because this entire proposal is meant to cut the money spent on the 6,000 PCA recipients, not increase the funding to buy more expensive services. For many PCA recipients, the hours of PCA coverage are crucial to maintaining their life at home. At a minimum, each person should be able to choose between continued PCA services and whatever other options DHS offers. Individuals or their families are in the best position to judge which services would be beneficial.

The Department of Human Services has not provided specific figures on the amount of money that will be shifted to each of the waiver programs. DHS is also unable to say how many of the 6,000 PCA recipients would be eligible for waiver programs. We do know that the MR/RC waiver has a waiting list of 1100 individuals. Some of those waiting may be PCA recipients who want waived services. If a large number of the 6,000 PCA recipients, many of whom are TEFRA eligible children, are not currently on the waiting list, get in line for the MR/RC waiver, DHS is simply substituting services with a waiting list.

The budget impact of the PCA "restructuring" is very difficult to find in documents provided thus far. The 25% cut in the hour limits in each case mix category, which was proposed in the Governor's January budget, cuts \$3.7 million in state funds (total of \$8 million with the federal match).

The new budget cut for elimination of TEFRA Medical Assistance of \$11 million in state funds undoubtedly includes PCA funding reductions plus other health services used by these children. There are three interrelated cuts affecting the PCA program before the Legislature: 1) lowering of PCA hour limits in each case mix

category by 25%, 2) PCA "restructuring," and 3) elimination of TEFRA M.A. for children. The combined reduction in Medical Assistance funds for health care services for children and adults with disabilities is over \$28 million.

If you are concerned about the Governor's budget proposals, we urge that you contact the Governor and your state senator and representative as well as the Department of Human Services to ask how you personally will be affected. For the name and address of your state senator, call 612/296-0504. For the name and address of your state representative, call 612/296-2146. The Governor's phone number is 612/296-3391. Governor Ame Carlson's address is: 130 Capitol, Saint Paul, MN 55155. Please make a copy of letters describing your current situation and what would happen to you if your services were cut and send it to Anne L. Henry, Minnesota Disability Law Center, 430 First Avenue North, Suite 300, Minneapolis, MN 55401-1780.

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Governor Proposes to Slash Health Care for Kids with Disabilities

By Anne L. Henry Minnesota Disability Law Center,
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Governor Carlson has proposed to eliminate a health care program for children with severe disabilities. If the Governor's cut is enacted by the Legislature, Newt Gingrich's proposal for orphanages will have to be taken seriously for Minnesota's most disabled children. The program to be abolished, called TEFRA Medical Assistance Option, was begun in 1988 and allows 3,900 families with children who have significant disabilities to buy into Medical Assistance benefits on a sliding fee basis. The importance of this coverage for kids with disabilities cannot be overstated. Prior to 1988, parents whose private health plans refused coverage for needed services (such as physical therapy, wheelchairs, home care), faced a draconian choice: quit work and impoverish the whole family in order to get Medical Assistance coverage for their child at home or place the child in an institution or foster home to obtain Medical Assistance coverage. The TEFRA Medical Assistance buy in option has been extremely important in allowing these children to remain with their families rather than in out-of-home placement.

The Governor is eliminating the TEFRA option apparently because costs have escalated from \$0 to \$25 million since 1988 when the program began. Is anyone besides state officials surprised that parents would seek help for their children with disabilities rather than place their beloved children in institutions or foster care? What about out-of-home placement costs which have been avoided by assisting families to keep kids with disabilities at home? According to state figures, families paid approximately 1/2 million dollars in fees to buy in to Medical Assistance coverage last year. The TEFRA program in combination with other community-based services for children with developmental disabilities saved \$20 million in 1990 alone over what would have been spent to care for a portion of these children in institutions. State institutions, which cost \$324 per day, housed 250 children with developmental disabilities in 1980; today there are less than 10 such children in our state institutions. State savings will evaporate if only 5% of TEFRA children are placed in state institutions. It would appear that the state shouldn't fill those state institutions with prisoners just yet.

Although the Governor's proposal to abolish the TEFRA program is combined with a

"reinvestment" of some of the savings in other disability programs, most of the 3,900 kids will get less service and up to 1/3 will not be eligible for anything at all. State officials contend that the families who are above poverty (\$15,150 for a family of four) and ineligible for continued Medical Assistance have the resources to buy health care directly or their private insurance will cover these children. Many families who use the TEFRA option have private health coverage. In fact, the law requires families to continue paying for private health coverage and use it first before Medical Assistance. Apparently Department of Human Services officials are unaware of the widespread insurance company and HMO practices which deny coverage to children with disabilities due to preexisting condition limitations or because their care is deemed "custodial."

The TEFRA option was established to fill a gap in private health coverage created by market place competition to dump more expensive cases off health plans' bottom lines. The TEFRA option's coverage of kids with disabilities reflects a Legislative judgment that investing in improving the functioning of kids with disabilities was beneficial for our state. Consideration of public good is in conflict with market forces that have led health plan companies and employer-purchasers to look short-term at their bottom lines and devise mechanisms to avoid costs, even for services which result in kids with disabilities learning to walk or communicate or grow up at home.

If this proposal passes, some families will again face Sophie's choice: live in poverty to get health care for your child with disabilities or place your child out of home and continue to work to support the rest of the family. Is this what the voters in last November's election wanted? When the Governor talks about giving children a very high priority during his administration, he's obviously excluding children with disabilities.